**House Committee on Ways and Means**
**Worker and Family Support Subcommittee**
**Hearing on "Making a Difference for Families and Foster Youth"**
**May 12, 2021**

**interACT: Advocates for Intersex Youth** is the oldest and largest organization in the United States dedicated to advocacy on behalf of young people born with variations in their sex characteristics—sometimes known as intersex traits. As an intersex person and Executive Director, I wish to thank the Subcommittee and Chair Davis for taking up the critical issues raised in this hearing, including the safety and well-being of lesbian, gay, bisexual, transgender, queer, intersex, and Two Spirit (LGBTQI+2S) youth in state care. In particular, we thank you for hearing the testimony of Weston Charles-Gallo regarding his own and other LGBTQI+2S youth's experiences in foster care. Mr. Charles-Gallo's testimony correctly points to the need for policy and culture change throughout the system that includes research, training, technical assistance, and nondiscrimination protections to ensure these youth are not left behind.

While there is so far less focused research on the experiences of intersex youth in foster care than those of other LGBTQI+2S youth, we do know that intersex youth face the same kinds of stigma, discrimination, and abuse. Many also suffer medical trauma from non-consensual early genital or sterilizing surgeries—sometimes with state agencies consenting on behalf of the child. Like all LGBTQI+2S youth, intersex youth can thrive if they are affirmed and supported. Congress and the Department of Health and Human Services (HHS) must act to protect and support all LGBTQI+2S youth, including intersex youth. Here we provide an overview of the challenges faced by intersex youth —including in the foster care system—and conclude with specific recommendations for HHS and Congress.

## Healthy Intersex Children Are Harmed by Stigma, Fear, and Non-consensual Surgeries

"Intersex" refers to people born with variations in physical sex characteristics—including genitals, gonads, chromosomes, and hormonal factors—that do not fit typical definitions of male or female bodies. **About 1.7 percent of the population is born with intersex traits, meaning millions of Americans are intersex, and there could be over 60,000 intersex births in the US every year, and thousands of intersex youth in foster care.**[1] While there is so far no systematic data on intersex foster youth, we know that other LGBTQI+2S generally are overrepresented in the system and may constitute as many as one in three foster youth.[2] Given that they face similar issues of stigma and discrimination, and may be more likely to be LGBTQ than non-intersex (endosex) youth, intersex youth are likely

[1] Melanie Blackless et al, How Sexually Dimorphic Are We? Review and Synthesis, 12 AM J HUM BIOL 151-166 (2000).

[2] M. Matarese et al., *The Cuyahoga Youth Count: A report on LGBTQ+ youth's experience in foster care* (Instit. for Innovation & Implementation, Univ. of Md. Sch. Social Work, 2021), https://theinstitute.umaryland.edu/our-work/national/lgbtq/cuyahoga-youth-count/; Theo G. M. Sandfort, *Experiences and Well-Being of Sexual and Gender Diverse Youth in Foster Care in New York City: Disproportionality and Disparities* (NYC Admin. Children's Servs., 2020), https://www1.nyc.gov/assets/acs/pdf/about/2020/WellBeingStudyLGBTQ.pdf; Laura Baams et al., LGBTQ Youth in Unstable Housing and Foster Care, 143 PEDIATRICS e20174211 (2019).

overrepresented as well. Despite being relatively common, "intersex" is still an unfamiliar term to many. This lack of awareness can cause feelings of stigma and loneliness for intersex people—and can also leave new parents feeling adrift if they happen to have an intersex baby.

**The vast majority of children born with intersex variations will not have immediate health concerns related to their differences. However, they are still frequently subjected to surgical interventions to make their bodies appear more "typical,"** absent any medical need. Most commonly occurring before the age of two, these operations include clitoral reductions, vaginoplasties, repeated penile surgeries, and even gonadectomies that can be sterilizing. Other consequences include chronic pain, urinary incontinence, sexual dysfunction, psychological trauma, and the chance that surgery will enforce a sex assignment that the child will not identify with later.[3]

**There are no proven medical benefits associated with performing these procedures before the intersex individual can participate in these weighty decisions about their own bodies and lives**, but parents frequently report feeling pressure to consent to these surgeries on their child's behalf. When parents do approve these surgeries, they often do so in a state of overwhelm and with incomplete information about the risks and alternatives, and what their child's medical needs might be as they grow up. interACT has heard from parents who pushed back, asked questions, and successfully advocated for their children to have the chance to make these choices for themselves, but we have also heard from other parents who are wracked with regret over consenting to irreversible and damaging procedures that could have been avoided if they had known more at the time. Outrageously, interACT has also been contacted about multiple cases in which the threat of removing an intersex child from their parents' custody was used to pressure parents toward surgery, or where removal proceedings were actually initiated due to the parents' refusal of unnecessary surgery on their child. In other cases, adoptive parents have contacted us about harmful surgeries that were carried out on their intersex children while still in state custody, before they had the chance to protect them.

**When intersex children are born, decisions to conduct unnecessary surgeries are often made based on social fears instead of evidence of medical need.** When other peoples' fears drive decision-making, the standards for what makes someone's body "healthy" or "normal" can become deeply flawed. Oftentimes intersex youth's bodies are compared to people who are non-intersex, cisgender, white, able-bodied, and thin. **The truth is, intersex children are already healthy. It's the ideas surrounding our bodies that need to be changed, not our bodies.** Take the idea that clitorises are supposed to come in one size. Not only is this problematic and another form of patriarchal policing of women's bodies, but it's also responsible for so many surgeries on intersex children—surgeries that remove clitoral tissue permanently just to fit this arbitrary ideal. (Penises come in different shapes and sizes, too, but no one's rushing to perform surgery because a penis is "too big.")

[3] NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE, *UNDERSTANDING THE WELLBEING OF LGBTQI+ POPULATIONS: CONSENSUS STUDY REPORT* (P. 296-323) (WASHINGTON: 2020); Rosenwohl-Mack A et al., *A national study on the physical and mental health of intersex adults in the U.S.*, 15 PLOS ONE e0240088 (2020).

**Despite condemnation from numerous United Nations bodies,[4] human rights groups,[5] and medical associations,[6] the practice of non-consensual surgery on intersex infants continues to this day in hospitals around the country.** The most in-depth report on the practice was released by Human Rights Watch in 2017 and identified New York City as a major center of non-consensual intersex surgeries. A provider in New York who has been identified in the press previously as a perpetrator of childhood sexual abuse, Dix P. Poppas, Chief of Pediatric Urology at Weill-Cornell/New York Presbyterian, has come under fire in the past not only for his performance of clitoral reduction surgeries on intersex children, but also for his follow-up "sensitivity testing" that involved applying a medical vibratory device to the surgically reduced clitorises of children as young as 6.[7] Despite this shocking practice, he continues to operate on his own patients.

**Non-consensual early genital or sterilizing surgeries also implicate civil and constitutional rights.** The Constitution protects the right of everyone—including children—to be free from unnecessary and unwanted medical procedures.[8] Early intersex surgeries frequently violate this right. The Constitution also subjects discrimination based on sex characteristics to heightened scrutiny.[9] This scrutiny is triggered when the reason for an early sterilizing or genital surgery is not a medical emergency (or the patient's request) but solely the goal of "normalizing" intersex traits.[10] Federal statutes applicable to ACF-assisted programs, including the Affordable Care Act, Title IX, and the Family Violence Prevention Services Act, also prohibit discrimination based on intersex traits.[11]

4 UN Office of the High Commissioner for Human Rights, *Background note on human rights violations against intersex people* (2019), https://www.ohchr.org/EN/Issues/Discrimination/Pages/BackgroundViolationsIntersexPeople.aspx; United Nations, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, Eliminating forced, coercive or otherwise involuntary sterilization: An interagency statement (2014), http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1; United Nations, Report of the Special Rapporteur on Torture, Juan E. Mendez, UN Doc. A/HRC/22/53 (2013), http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

5 Amnesty International, *First, Do No Harm: Ensuring the Rights of Children Born Intersex* (2017), https://www.amnesty.org/en/latest/campaigns/2017/05/intersex-rights/; Human Rights Watch, *"I Want to be Like Nature Made Me": Medically Unnecessary Surgeries on Intersex Children in the US* (2017), https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us; Physicians for Human Rights, *Unnecessary Surgery on Intersex Children Must Stop* (Oct. 20, 2017), https://phr.org/news/unnecessary-surgery-on-intersex-children-must-stop/.

6 American Academy of Family Physicians, Genital Surgeries in Intersex Children (July 2018), https://www.aafp.org/about/policies/all/genital-surgeries-intersexchildren.html; GLMA: Health Professionals Advancing LGBTQ Equality, Medical and Surgical Intervention of Patients with Differences in Sex Development (Oct. 3, 2016), http://glma.org/index.cfm?fuseaction=Feature.showFeature&CategoryID=1&FeatureID=796; Massachusetts Medical Society, Evidence-Based Care of Individuals Born with Differences in Sex Development (DSD)/Intersex (Dec. 7, 2019); http://www.massmed.org/News/Press-Releases/Massachusetts-Medical-Society-announces-policies-on-opioid-use-disorder,-intersex-children-and-e-cigarettes/#.Xz7jNS2z0nU; Michigan State Medical Society, Opposing Surgical Sex Assignment for Infants with Differences of Sex Development, Res. 12-18 (2018), https://www.msms.org/hodresolutions/2018/12.pdf.

7 Human Rights Watch, *"I Want to be Like Nature Made Me": Medically Unnecessary Surgeries on Intersex Children in the US* (2017). *See also* Yang, J., D. Felsen, and D.P. Poppas, Nerve sparing ventral clitoroplasty: analysis of clitoral sensitivity and viability, 178 J UROL 1598-601 (2007).

8 *See* Parham v. J. R., 442 U.S. 584, 600 (1979) ("It is not disputed that a child, in common with adults, has a substantial liberty interest in not being confined unnecessarily for medical treatment.").

9 *See*, *e.g.*, Bostock v. Clayton County, 140 S. Ct. 1731 (2020); Sessions v. Morales-Santana, 137 S. Ct. 1678, (2017).

10 Nondiscrimination in Health Programs and Activities; Final rule, 81 FR 31375, 31389 (May 18, 2016) ("[T]he prohibition on sex discrimination extends to discrimination on the basis of intersex traits or atypical sex characteristics. OCR intends to apply its definition of 'on the basis of sex' to discrimination on these bases.").

11 20 USC § 1681; 42 USC §§ 10406, 18116.

**These irreversible and often high-risk early surgeries are performed to conform intersex bodies to gender expectations, often with patients having little or no say** in this personal decision to determine what, if any, surgery or other treatment is appropriate for them. These surgeries may be well-intentioned, but they surgeries are carried out with the assumption that this is what children will want as adults, when we know from the many heart-wrenching stories of intersex adults who grew up to wish they had not had these surgeries that this assumption simply cannot be safely relied upon. Good intentions aren't enough: Parents need to be properly educated and made aware of the risks associated with these surgeries, state agencies must safeguard the autonomy of intersex youth by abstaining from decisions about surgeries that are not urgently necessary for the child's physical health, and doctors should be accountable for the information and treatment options that they offer.

## Intersex Youth Are Harmed by Bullying, Harassment, and Abuse by Peers and Adults

**While there has been little research on the experiences of intersex youth in foster care specifically, existing research from other settings suggests they face many of the same difficulties as other LGBTQI+2S youth.** One study of 272 Australian intersex adults about their schooling experiences found that two-thirds reported some form of victimization, most reported suicidal ideation, only a quarter reported positive educational experiences, and they were far more likely than their peers not to complete secondary school.[12] Australian intersex adults also report more social isolation in both elementary and secondary schooling than their non-intersex (or endosex) peers.[13] In the United States, intersex advocates have spoken about their own experiences in school: "I've overcome doubts and fears that I've held onto for most of my life. I always let my intersex traits hold me back from opportunities because of severe bullying. I learned to hide in the background so that people wouldn't notice me. In the process, I lost my voice and my confidence. I forgot who I was and what I was capable of becoming."[14] This advocate was able to find support through intersex communities and become interACT's first communications intern, and ultimately its Director of Engagement.

**Intersex youth report being singled out for bullying because of their visible sex characteristics.** For example, youth born with Congenital Andrenal Hyperplasia may be initially assigned female at birth, and may later develop secondary sex characteristics typically considered masculine—often earlier than their peers. One youth advocate shares:

> I knew other girls didn't grow facial or body hair like me, but I didn't understand why. Classmates called me "man voice" and made fun of my flat chest and muscular arms. I woke up two hours early every morning to make sure I had time to remove every visible hair from my face, all for fear of someone catching a glimpse of my stubble. I didn't actually notice the things that made my body different until other people pointed them out, and then it just stuck with me.[15]

[12] Tiffany Jones, *The needs of students with intersex variations*, 16 SEX EDUC. 602 (2016).
[13] Mandy Henningham & Tiffany Jones, Intersex students, sex-based relational learning & isolation, SEX EDUC. (2021). DOI: 10.1080/14681811.2021.1873123.
[14] InterACT, Bria Recaps Their interACT Internship (Feb. 4, 2020 https://interactadvocates.org/internship_recap/.
[15] *Id.*

**For other intersex youth, different treatment can start when they choose to confide in a friend or adult about their intersex traits.** One interACT Youth member reports: "A friend told me not to go into the girl's locker room anymore after I told them I'm intersex."[16] Classroom discussions of gender, sexuality, and human development that leave out intersex realities can be painful for students in themselves, and also lead to bullying and harassment. "I walked out of health class crying last year," reports another interACT Youth member.[17]

**Like transgender youth, intersex youth can face harassment and discrimination in access to restrooms and locker rooms.** In a brief submitted to the Supreme Court, one former student relates their apprehension when their body began to masculinize at puberty. This student tried to avoid using restrooms altogether, but was ultimately barred from them by their school:

> [I] was in a boys' restroom, and someone saw that I went in there, and then complained to my counselor, who then said "Well, you can't use the boys' restroom, so you have to use the girls' restroom." And I was like "ok, fine, whatever." But … there [were] then complaints that I was using the girls' restroom. And I was told, "Well, you can use the nurse's restroom."
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> Now, … the nurse was on the complete opposite side of the entire building …. So if I was in the middle of class, I would have to leave, and I would be gone for 10-15 minutes, so of course my teachers didn't like that. So I was told "You can't use the nurse's restroom …. There is a single-stall restroom in the special education area, which is near where your classroom[s] are, so you can use that one." And I was like "fine, ok." And I used that one for a bit and was then told that I couldn't use that one….
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> At that [point] … I was told "Well, you don't have a full school schedule, so you can just hold it." So yeah, for the last semester, at least, I just wasn't allowed to use the restroom at the high school at all.[18]

**This harassment has lasting effects on intersex youth, often compounding medical and other traumas.** One youth reported that after being bullied at school, including having a milkshake thrown on him, "Even today I don't like to be touched, so don't touch me."[19]

**Bullying and mistreatment are driven by the same stigma and biases that motivate "normalizing" surgeries.** The specter of one day being harassed in the locker room has historically been invoked as a justification for medically unnecessary early surgeries. In effect, doctors have views the harmless presence of intersex traits as a "social emergency," and believed surgeries would prevent children from experiencing stigma, isolation, and trauma as they grew up. However, early surgery often produces the opposite effect, teaching intersex youth from the beginning of their lives that there is something wrong with them about which they should feel ashamed. Bullying against intersex youth should be addressed in the same way as other types of bullying—with social interventions aimed at stopping the abusive behavior and encouraging acceptance—rather than through unnecessary and non-consensual surgery.

[16] interACT, What We Wish Our Teachers Knew (2018), https://interactadvocates.org/wp-content/uploads/2018/07/BROCHURE-interACT-Teachers-final.pdf.

[17] *Id.*

[18] Brief of interACT: Advocates for Intersex Youth, et al., as *Amicus Curiae* in Support of Respondent, Gloucester County School Board v. G.G. ex rel. Grimm, No. 16-273 (U.S. Mar. 2, 2017).

[19] Jack D. Simons, Jose-Michael Gonzalez & Melissa Ramdas, Supporting Intersex People: Effective Academic and Career Counseling, 14 J LGBTQ ISSUES COUNS. 91-209 (2020).

## There's a Better Way—Allowing Intersex Children to Grow and Thrive

**Doctors, parents, and agency officials charged with making medical decisions on behalf of foster youth should know that delaying non-emergency genital and gonadal surgeries so an intersex person can make their own decision is the safe and ethical choice.** We need more of our doctors, parents, and child welfare professionals to know that our bodies are not broken and don't need to be "fixed." There are many intersex people living healthy and fulfilling lives without surgery.

**The largest children's hospitals in Boston and Chicago— Boston Children's Hospital, Lurie Children's Hospital—have committed to ending certain harmful intersex surgeries** on children who are too young to participate in these life-altering decisions about their own bodies.[20]

**And in a step that deserves to be replicated nationwide, New York City recently passed legislation to create a public education campaign** to better educate both families and medical providers on intersex variations and the potential harms of unnecessary early surgeries.[21] New York State is considering similar legislation. **The federal government should undertake a similar campaign** nationwide, building on educational resources for providers and families developed by the National LGBTQIA+ Health Education Center and interACT.[22] This education effort should build on the expertise of the Offices of Women's Health, Minority Health, and the Surgeon General, but should include a prominent focus on the child welfare system and other programs assisted by ACF. It should also include Military Treatment Facilities operated by the Department of Defense, where more than 50,000 babies are born each year.[23]

**Like other marginalized youth, intersex youth can thrive when they are affirmed and supported.** Like their peers, many strive for excellence in school, sports, community involvement, and helping others—but struggle in the face of medical trauma, discrimination, and the need to rely on adults who often have little knowledge or understanding of their experiences.[24] Intersex youth have many of the same needs as transgender youth, such as support form adults, and peers, inclusive policies and rules, equal access to facilities, the ability to easily update official records if needed. Intersex youth also need to have adults in their lives who understand the normal and healthy variations in sex development, to receive "clear messages that a [program or setting] welcomes intersex people; [and] to know that confidentiality will be respected."[25]

[20] Lurie Children's Blog, Intersex Care at Lurie Children's and our Sex Development Clinic (July 28, 2020), https://www.luriechildrens.org/en/blog/intersex-care-at-lurie-childrens-and-our-sex-development-clinic/; Kimberly Zieselman, Boston Children's Hospital's Change on Intersex Surgeries was Years in the Making (October 23, 2020), https://interactadvocates.org/boston-childrens-hospital-intersex-surgery/.

[21] N.Y.C. Int. No. 1748-A (2021).

[22] National LGBTQIA+ Health Education Center, *Affirming Primary Care for Intersex People* (2020), https://www.lgbtqiahealtheducation.org/publication/affirming-primary-care-for-intersex-people-2020/; interACT, *"What We Wish"* Brochure Series by Intersex Youth, https://interactadvocates.org/resources/intersex-brochures/.

[23] Military Health System, Number of Deliveries in Military Hospitals (October 7, 2016), https://www.health.mil/Reference-Center/Reports/2016/10/07/Number-of-Deliveries-in-Military-Hospitals-v2.

[24] Jack D. Simons, Jose-Michael Gonzalez & Melissa Ramdas, Supporting Intersex People: Effective Academic and Career Counseling, 14 J LGBTQ ISSUES COUNS. 91-209 (2020).

[25] Malta Ministry for Education and Employment, Trans, Gender Variant and Intersex Students in Schools Policy, 14 (2015), https://education.gov.mt/en/resources/Documents/Policy%20Documents/Trans,%20Gender%20Variant%20and%20Intersex%20Students%20in%20Schools%20Policy.pdf.

## HHS Should Act to Protect and Support Intersex Foster Youth

**There is much that HHS can and should do to protect and support intersex foster youth,** as well as all LGBTQI+2S foster youth, and those at risk of entering the system. We urge the Subcommittee to continue its oversight of HHS and ACF to ensure these steps are pursued swiftly and robustly.

**We strongly support, and urge HHS to swiftly implement, the recommendations of the Every Child Deserves a Family Campaign.**[26] These comprehensive recommendations outline how HHS can use its existing resources and authorities to make real, meaningful change in the lives of the over 120,000 foster youth who are LGBTQI+2S.

**HHS and ACF must ensure that all efforts to protect and support LGBTQI+2S youth include intersex youth, including** nondiscrimination rules; guidance, training, and technical assistance; data and research; and **taking action to prevent unnecessary and non-consensual genital or sterilizing surgeries of infants and children in state care**, as well as ensuring trauma-informed care for foster youth who have been subjected to such procedures and other medical trauma.

First, ACF should institutionalize this work through **dedicated staffing, funding, and stakeholder input**, ensuring that the concerns and voices of intersex youth are included throughout, including:

- Establishing a Senior Advisor to focus on the needs of LGBTQI+2S youth.
- Establishing a National Resource Center for LGBTQI+2S Youth.
- Establishing an LGBTQI+2S Advisory Committee.
- Hosting convenings on the needs of LGBTQI+2S youth.

Second, ACF should **provide guidance, resources, and requirements for all its personnel and programs to support LGBTQI+2S youth**, ensuring that all policies, materials, and training content are responsive to the needs of intersex youth, including:

- Issuing guidance for child welfare services and other ACF-funded programs on nondiscrimination and best practices.
- Training requirements and resources for ACF staff and ACF-funded programs.
- Funding demonstration projects for models for prevention and improving outcomes for LGBTQI+2S youth, including models to promote family, health care provider, and agency education and acceptance for intersex children and to discourage unnecessary early surgeries.

Third, ACF should **build the knowledge base for efforts to support LGBTQIA+2S youth**, including:

[26] Every Child Deserves a Family Campaign, Transition Recommendations for the Next Presidential Term (Dec. 2020), https://everychilddeservesafamily.com/transition-recommendations.

- Developing, testing, and implementing inclusive data collection measures for sex assigned at birth, gender identity, intersex status, and sexual orientation—building on a forthcoming consensus study from the National Academies of Science, Engineering, and Mathematics.[27]
- Supporting LGBTQI+2S-inclusive and -focused research—building on the National Institutes of Health's growing intersex research portfolio.[28]
- Conducting a 50-state study of policies, procedures and practices that may create barriers for LGBTQI+2S youth or families—including in education, training, informed consent, and health care decision-making practices with respect to intersex infants and children, as well as transgender adolescents and young adults.

Fourth, **ACF should adopt rules or guidance to ensure informed consent to medical treatment for intersex foster youth, including prohibiting early sterilizing or genital surgeries** absent an immediate risk of physical harm that requires surgery to be performed.

Finally, **ACF should work with other HHS components to create a public education campaign for families and ACF-assisted programs** to increase understanding and acceptance of intersex traits, ensure full informed consent, and prevent unnecessary and non-consensual early surgeries, including by:

- Providing guidance, technical assistance, and training to states and ACF-funded programs.
- Creating and disseminating educational materials for ACF-funded programs, families, and medical providers.

## Congress Should Act to Protect and Support Intersex Foster Youth

While there is much that HHS can and must do immediately to protect intersex and other LGBTQIA+2S who are in, or at risk of entering, the foster care system, Congress must act to ensure protection and support for these youth are explicit, comprehensive, and permanent.

**We join Mr. Charles-Gallo and over 200 child welfare, child health, faith, and civil rights organizations in urging Congress to pass the John Lewis Every Child Deserves a Family Act**. This lifesaving legislation would permanently codify nondiscrimination protections and the responsibility of HHS to provide focused guidance and technical assistance and ensure inclusive data collection and training for the foster care system, including through a National Resource Center.

**The Act must be strengthened to expressly include protections and support for intersex children and youth**, throughout all the bill's provisions. In light of the historical invisibility of intersex youth and the additional, unique harms many face early in life from medical trauma and mistreatment, this express inclusion is vital to ensure the legislation achieves its goals.

[27] National Academies of Sciences, Engineering, and Medicine, Measuring Sex, Gender Identity, and Sexual Orientation for the National Institutes of Health, https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health (accessed May 24, 2021).

[28] National Institutes of Health, DSD & Intersex Research Portfolio (2020), https://dpcpsi.nih.gov/sites/default/files/SGMRO_SnapshotDSD-Intersex_508.pdf (describing 34 projects comprising 8.9% of NIH's SGM portfolio for FY 2018).